Information for Research Study Participants

What is an IRB?
The Institutional Review Board (IRB) is a group of people with varying backgrounds that review and approve research involving human participants to ensure participants are treated ethically. The IRB includes scientists, non-scientists, and people from the community. The IRB serves to protect rights and welfare of research participants before and during the research study. For example, the IRB makes sure that any risks are as small as possible and that any benefit from the research outweighs any risk to the participant.

The IRB does not decide for you whether to take part in a research study. That is solely your decision. The IRB’s focus and main purpose is to ensure potential participants can make an informed decision and to protect those who participate.

Why should I take part in a research study?
There are a wide variety of research studies being conducted at any given time. Through research, advances have been made in physical and social sciences. Research takes place in many locations both on and off the University campus. It is important to note that other institutions may also recruit participation from the University at Albany, but the University at Albany IRB only reviews research conducted by University at Albany researchers.

When considering participating in a research study, remember that participation is completely voluntary – an individual can choose not to participate, or if they do decide to participate, they can choose to stop participating at any time. Ultimately, the decision rests with the participant and what they are comfortable with. Most of the research undertaken by the University at Albany is social, behavioral, or educational research, but there are also bioscience-based studies as well.

Will I benefit from being in a research study?
The research study may or may not benefit you personally. It may only provide general information that will help future generations. It will depend on the nature of the study.

Are there risks to being in a research study?
Sometimes research procedures and treatments may cause discomfort or bad side effects.

- **Physical risks**: a physical risk may result from the involvement of physical stimuli such as noise, electric shock, heat, cold, electric magnetic or gravitational fields, etc.

- **Psychological risks**: include the production of negative affective states such as anxiety, depression, guilt, shock, and loss of self-esteem and altered behavior.

- **Social/Economic risks**: include alterations in relationships with others that are to the disadvantage of the subject, including embarrassment, loss of respect of others, labeling a subject in a way that will have negative consequences, or in some way diminishing those opportunities and powers a person has by virtue of relationships with others.

- **Economic risks**: these include payment by subjects for procedures not otherwise required, loss of wages or other income and any other financial costs, such as damage to a subject's employability, because of participation in the research.
• **Loss of Confidentiality**: in all research involving human subjects, confidentiality of identifiable information is presumed and must be maintained unless the investigator obtains the express permission of the subject to do otherwise. Subjects have the rights to be protected against injury or illegal invasions of their privacy and to preservation of their personal dignity.

• **Legal risks**: legal risks exist when the research methods are such that the subject or others will be liable for a violation of the law, either by revealing that the subject or others have or will engage in conduct for which the subject or others may be criminally or civilly liable, or by requiring activities for which the subject or others may be criminally or civilly liable.

Some of the risks may not be fully known at the beginning of a study. The research team will discuss the known risks with you so you can make the decision to participate or not.

**What Is informed consent?**
Informed consent is the process of learning the key facts about a research study before deciding whether to volunteer. Agreement to volunteer should be based upon knowing what will take place in the research study and how it might affect you. After learning the key facts about a research study, you can decide whether to be a volunteer in the study.

**What questions should I ask before agreeing to take part in a research study?**
Before deciding to volunteer to take part in a research study, it’s important to know as much as possible about the research study. If there are any issues that concern you, be sure to ask questions. You might want to write your questions down in advance. The following is a list of sample questions. Not every question will apply to every research study.

✓ Who is doing this research study and what question(s) might it answer?
✓ Will this research study help in understanding of a topic, contribute to knowledge? If so, how?
✓ What will participation involve, entail?
✓ What could happen to me, good and bad, if I take part in the research study?
✓ How long will this research study last?
✓ What will happen to any specimens that I give?
✓ Who has reviewed and approved this research study?
✓ What other options or choices do I have if I decide not to take part in this research study?
✓ Will I be charged anything or paid anything to be in this research study?
✓ If I decide to participate in this research study, how will it affect my daily life?
✓ What will happen to me at the end of the research study?
✓ Will I be told the results of the research study?
✓ Who will find out that I am taking part in this research study?
✓ How do I end my participation in this research study if I change my mind?
✓ Whom do I contact for questions and information about the research study?

Remember, if you do not understand the answer to any of your questions, ask again. Ask the person to explain the answer in a way you can understand it. If you forget the answers to the questions during the research study, just ask them again.
Who will see my information?
The information in your research study record will be confidential. Information will be given only to the people who need it. This includes researchers and staff who carry out the research study. This may also include the Institutional Review Board (IRB), the company or group funding the research study, or various government oversight agencies. It is important for these groups to be able to look at your records, so they can ensure that the research study is conducted using acceptable research practices.

How do I withdraw from a research study?
To withdraw from a study, contact the principal investigator. The contact information for the principal investigator can be found in the informed consent information that has been provided to you.

What if I have a concern or a complaint?
If you have any concerns or complaints about a research study you are participating in or have been asked to participate in, contact the University at Albany IRB at (866)-857-5459 or RCO@albany.edu